

## **Minutes of October 16, 2001**

### **Web-based Resource Center Work Group Conference Call**

On the call:

Suzie Burke-Bebee, Centers for Disease Control and Prevention (CDC) / National Center for Health Statistics (NCHS) / Office of Data Policy and Standards

Tom Doremus, Public Health Foundation (PHF)

Marjorie Greenberg, CDC / NCHS / Office of Data Policy and Standards

Vicki Hohner, Washington State Department of Health

Hetty Kahn, CDC / NCHS / Office of Data Policy and Standards

Michelle Williamson, CDC / NCHS / Office of Data Policy and Standards

Note: The minutes were edited for brevity sake.

### **Comments on Content**

Marjorie: This work group will develop the conceptualization for the Web-based Resource Center and some of the content. Other Consortium work groups or contracted entities will be the primary developers of the content.

Tom: Support materials developed for the calls can be considered for content. In the process of looking over the web sites, several have good content, but it is not packaged for the needs of the divergent users. The current content available can create naysayers as the visitors to the sites must swim through the words to find some relevant information. Bob's work with Denise and NAHDO, creating 'to-the-point' fact sheets and topic focused pages that will provide needed resources with limited search time will be a welcome resource for our site.

Marjorie: The packaging and integration of content is an area that our work group really needs to work on.

Tom: We can use the nuggets of pertinent information from currently available sites and re-cast it (rewording as needed to prevent copyright infringement) to fit into our areas of focus.

Marjorie: Bob reported that his project with NAHDO to provide content is progressing well. I think the 'data standards 101' (the basics) that Bob is working on serves as a good introduction to the implementation guide.

### **Web Site / Content Categories and Navigational Structure**

Tom: There are two sets of category suggestions that are in addition to the ones put forth by Marjorie and Michelle. I added three new categories to the 'subject' category set to reflect general information and implementation content sites.

Marjorie: I wanted to change my original subject set titles from HIPPA and Non-HIPAA to HIPAA and HIPAA Plus. Clinical standards really are part of HIPAA.

HIPAA includes the requirement that the national committee develop recommendations for clinical standards and laboratories fits in here. NEDSS is trying to be compliant with HIPAA.

Tom: I included Non-HIPAA data standards sites to help serve the needs of practitioners that we want to warm up to HIPAA. Does anyone think we can expand on the current categories in the subject sets?

Vicki: It is difficult for people to wrap their arms around standards. Standards are often not stand-alone. They are embedded in other parts. The current sites lack focus on standards. We need some sort of umbrella to pull the useful pieces under.

Tom: Can we use the umbrella idea for images to help visitors navigate our site.

Vicki: The umbrella idea is more conceptual than visual. Pull standards together and relate to them in a meaningful way.

Suzie: Looking at Bob's three categories, collection authority, technical considerations, and privacy/security considerations, that each of those has been broken out equally. He said that education is a very important part of a standard, whether it is voluntary or proprietary. And, the Federal and state issue plays into the HIPAA and HIPAA Plus idea. I was thinking of using Bob's category breakout and tagging the HIPAA content, so that if a visitor wanted HIPAA material that (for example) may fall under 'collection authority,' although there may be some duplication here into the technical considerations or privacy and security area, there would be some means for the user to tease out the HIPAA material, versus the HIPAA Plus. To actually use the umbrella idea of something more than HIPAA, but still what will call attention to the material and keep the visitor interested will be the HIPAA content or how close they are to HIPAA.

Vicki: If someone visits and they are looking for standards information, whether or not they are familiar with HIPAA or non-HIPAA, will our site help direct them there?

Suzie: That is where I think the visuals will come in, something that will aid in directing people (i.e., using a hippopotamus character to identify HIPAA specific information) to help in explaining the 'lay of the land.'

Tom: We were talking about using roles and audience types as a way of steering visitors, possibly as broken out in the third set of categories in the handout. Another method that may be helpful would be to have a set of yes/no questions that, with a positive response would steer the person to a list of links related to their needs. As an example, the question could ask if the visitor was a government employee at a local health department interested in exchanging data with the private sector. If the visitor clicked on 'yes' the links that appear would cover areas pertinent to this activity, such as privacy and security provisions of HIPAA, and as much as possible

relate directly to the visitors entity and jurisdiction level (in this case a local health department).

Michelle: I am not sure whether you are focusing on subject or role categories. Are we opening the option of doing both. There are many sites that allow you to search various ways. We could build something that includes searching by subject, roles, and using questions. There could be a tab that is used to choose subjects, which could lead to HIPAA and HIPAA Plus links. The other two tabs could be 'by role' and 'by frequently asked questions' respectively.

Tom: Some people have a sense of what they are looking for and can reach relevant information via a subject category. Others that may be less experienced with the standards process may find the FAQ helps them to zero in. The questions could be sectioned by jurisdiction (i.e., local, state, federal). There are a number of ways we could parse out any of the navigational modes (subject, roles, questions) to quickly lead the visitor to information that fits their needs.

Note: Currently there are two subject breakouts (NCHS team and Bob's).

Michelle: I agree that we can open the door to suit the needs of any visitor that comes to the site. We can even ask basic up-front questions such as "Interested in HIPAA information, but not sure where to look?" to direct them to relevant links.

Vicki: As part of this site would we also want to post information on what we are trying to focus on with these standards. Let the people know what our intent is. Does the Consortium plan to bring all the standards together? Are we focused on HIPAA Plus, etc.

Marjorie: A home page that provides our mission and vision?

Vicki: Something that would also identify other standards efforts that blend with ours or that build on HIPAA. Of special interest would be standards efforts that try to condense more standards into fewer standards.

Marjorie: I like the 'questions' approach (i.e., "Who are you?") and the idea that there can be more than one approach. I do not think there is much out there that (for example) an employee a local health department can, via a few clicks, have information that speaks to their needs.

Tom: Sometimes there is not an answer at a web site, in a book, or printed elsewhere. Even though our current and future funding may not allow for a 'virtual 24/7 help desk,' we may consider providing an e-mail link that allows visitors to send questions. These questions could be addressed as time and resources allow, and the questions may serve as indicators of content that would be useful for posting at the site. This is not an assignment that I think should be delegated to

WRC WG members, but it is something that should be considered for the conceptual model of the site and identified up-front to identify realistic funding needs.

Michelle: As a continuation of Vicki's comments, we can consider something general that tells visitors what they can expect to find at the site. Also helpful would be a brief statement under each category to explain the nature of the category.

Tom: Sounds like an action item. I welcome all members to work with me in brainstorming on explanations for each category.

Tom: Any other comment on the content categories and navigational structures?

Note: No comment

### **Suggested Web Sites**

Tom: Ginny had provided information on sites in the NEDSS and clinical standards subject areas and I have done the same for some of the other sites. These are draft versions of suggested sites. Between now and the next call, other members have indicated they will be providing site suggestions. As we move along, we can determine when a site has limited information that would best be re-cast to fit into our site, thereby not sending visitors 'out the back door' to sites they may become lost in or discouraged altogether from their search process.

Many of the sites I reviewed fit under multiple categories. Within the annotation for each site, I identified information pertinent to currently named categories.

Are there any comments on the sites identified on the handout?

Michelle: Did you find any sites that related to administrative data?

Tom: I did not review any to-date. I am sure there are some available that at least include this information in a broader site.

Hetty: I have administrative site information that I will send you.

Marjorie: It would be good to include NUBC and NUCC. They maintain a number of code sets. You have to be a subscriber to obtain the greater detail on parts of the sites. I don't think we need to exclude subscription sites as long as they are not commercial and they are at a reasonable cost and easily accessible.

Tom: I have found subscription services to be well constructed and maintained. If we know a site is 'pay-to-surf' we can include dollar signs (\$\$\$) similar to tour guidebooks.

Would we want to take part in any scoring or evaluation of sites?

Suzie: I would shy away from this because of the liability and the maintenance involved. We can consider doing what some bookstores do and provide ratings from someone else or identify sites that others view on the same topic. There has been a lot of discussion along these lines on the government infrastructure team.

Michelle: It would be good to have a method of feedback so we can learn if the visitors find particular areas useful, etc.

Suzie: The survey form for feedback should be optional if used. Some sites require survey completion as a requirement for moving forward. Others disable the 'back-button.' Visitors do not appreciate both of these techniques.

Note: a few members suggested that any feedback be reviewed to assure that only legitimate and reasonable responses are posted.

Michelle: Suzie, Hetty and I would like to add administrative data links to X12, HL7, and WPC.

Suzie: There is a Georgetown privacy group.

Vicki: I believe it is [privacy.org](http://privacy.org). See also [www.hhs.gov/ocr/hipaa](http://www.hhs.gov/ocr/hipaa).

The WEDI SNIP is critical to HIPAA implementation.

Tom: Please review the Privacy and Security section and comment on the style and content of the annotation.

Vicki: I think it is great for people who are just getting their feet wet.

Tom: I am thinking it would be wise to separate the categories into their own web pages.

Marjorie: Regarding clinical standards, I was just communicating with Jeff Blair, who is on the National Committee of Vital and Health Statistics. He is heading up their effort on recommendations to the Secretary for clinical standards. He could be helpful in this regard. His e-mail address is [Jeffblair@medrecinsp.com](mailto:Jeffblair@medrecinsp.com).

Suzie: Isn't there a WEDI URL.

Vicki: Yes, we found good information there on privacy, security, Medicaid, and more.

Suzie: Also consider CTRI, MRI, HEMA, and AHA.

Marjorie: AHA maintains Coding Clinic. You may have to subscribe to it, but it is the definitive guide to using ICD 9 CM.

Suzie: Physicians are a user group that we really want on board, buying into standards. Does the American Medical Association (AMA) have a section on standards? The American Nurses Association (ANA) is promoting standard nomenclature.

Tom: At this stage of the program, any site we can put on our potential list is useful. As we fine-tune the architecture and information flow within the site, the 'keepers' will become more evident. Although it may be in the interest of the standardization mission to keep visitors at our site rather than lead them to robust sites that may take them on tangents far removed from promoting data standards. What may be useful is a framed page that would keep our major navigational links visible on the screen as the visitor surfs to other web sites.

We can build our site's worth by increasing the usage (more visitors and more time at our domain by individual visitors).

Suzie: We need to be concerned with potential for clutter that may come from sponsorship (i.e., logos and company names etc. on the sides of the visitor's screen). Are we considering asking for sponsorship from the commercial sector?

Tom: I think that it would be good to see the plan that evolved from the funding work group. Suzie, you had identified a great potential funder when we talked about this in July.

Suzie: Start-up money is one thing, but maintenance money is another. I agree, it would be good to see what comes from the funding work group.

I sent Elliott Stone a document on e-health that had five to ten pages of resources for grant funding.

Marjorie: This is a time when the needs of public health infrastructure are at center stage.

Suzie: Tom, I see you have LOINC listed under HL7. Do we want to list LOINC separately? Some of the links you listed have additional links within their site.

Tom: I think it could go either way. I think it is OK to put links within links. The main link could take the visitor to broad-based information, and the intra-site links could direct them to focused information. The links can also be separate.

Suzie: I don't see that we have the DSMOs and Attachments, which would be the 'soon-to-be-HIPAA.'

Tom: I can add those.

Suzie: Attachments would be an ideal place to put LOINC (through Regenstrief Institute).

Suzie: HISSB no longer exists, so links to HISSB information will need to be reviewed.

Tom: How does the group feel about the annotation regarding visiting health data staff from local and state health agencies. Is it too much, too little? Is the material too basic or to the point? Comments to these questions could go on the listserve.

Marjorie: We may want to have a glossary. We did a partial glossary for our education strategy report.

Vicki: WEDI SNIP has a really nice one. We use it extensively.

Tom: A link can be set to open up a window within the window being viewed (but at a smaller size). This could be a method of bringing a glossary up for easy use, with the ability to minimize this smaller window when desired.

Suzie: Here are some ideas about the user friendliness of the site. For the Consortium site, we make a pdf version of material that allows for printing. However, HTML pages can be formatted specifically for printing and are less likely to freeze up a computer during the printing process. Ease of printing, using only the browser software, increases the likelihood that the visitor will continue using the Resource Center.

Note: When Acrobat Reader loads it puts an added memory strain on some systems with low memory (RAM).

Tom: This idea goes to the heart of what our job is here, serving as facilitators to the visitor experience.

Any other comments on the sites at this time?

Note: no comments

Tom: If any of you who are not on the site research team come across a site that you think is viable, including any suggested annotation (while the site is fresh in your mind) your contribution is welcome. I will likely include sites that were identified in the Consortium Education Strategy report.

### **Search Utility**

Suzie: Off the subject, but of importance; is there a search capability planned?

Tom: I would think it would be essential. A 'low-tech' search component is easy to add to multiple pages with simple runs of text and few mini-programs, java-scripts, etc. However, with the many ways that we envision to make the site user friendly (printing options, image maps, text submission interfaces, etc.) the search component will likely be more complex to set-up. Ideas for our search component's needed capabilities will likely evolve as we determine the best way to direct traffic at the site (in cases where self-direction may not be very productive).

### **Portal Technology**

Suzie: Do we want to think about using 'portal' technology or features. One of the nice features of portals is the ability for a user to tailor the web site to their interests (create pages, positioning of content, etc. with the resources available at that site).

Tom: It sounds very appealing to users, but may be better held as a second tier or second generation project after our initial content postings. I don't see many portals using that technology at this time, so I am guessing that it is resource intensive.

Suzie: If we enlist the support of a major technology company, we may be able to use their capacities and software to make it work.

Suzie: CMS is setting up something like this for Medicare.

Tom: If we could offer this it would help attract and retain visitors. They would probably like to see updated news addressing their needs. It may take time and resources, but even the funders will appreciate a site that meets the mission, and put their money to work with tangible results.

Suzie: The personalization is a real attractive component and once the portal is built, the user maintains their own pages.

### **Survey Questions**

Tom: Our next area of business is discussing suggested questions that will help us learn the educational needs of public health practitioners and the educators that serve them. I developed a draft questions page, which is part of the support documents I sent out. Are there any comments on the knowledge-based area?

Suzie: When you ask if they are familiar with HIPAA (Number 1 & 7) we are also interested in knowing who is implementing HIPAA, and what parts of HIPAA, and when.

Marjorie: It may be good to preface our questions with a short primer on data standards, (their nature as fundamental building blocks, their use of classification systems, etc.) to prepare the field. I will send you some lines on this.

Tom: I agree that it is wise to warm the participants into the survey.

Michelle: After the primer, we may want to ask them "Have you attempted to obtain information via the Internet on any data standards issues? If so, please specify the information desired." Also we could ask "Were you successful in accessing any resources?" If they were not, we will know what they were looking for, which will help us know the needs to satisfy with the Resource Center.

Marjorie: Has anyone seen a site that included information geared toward standards in public health that says standards are not necessary?

Tom: I have not seen any yet, but naysayers and devil's advocates provide us with clues on how to improve.

Marjorie: Actually I was thinking along the lines of a site that says "This is already being done so a new site like WRC is not needed."

Note: None on the call had come across such a site.

Suzie: Someone told me after leaving a standards and security meeting that there was a group connected to public health that is putting together an enterprise model. It would benefit the Consortium to know that a group is working on a business model for public health.

Tom: Any comments on the Web capacity section of the suggested questions?

Michelle: I think we need to add unknown. Some may have these components and features, but not know.

Tom: Good point, it may be helpful to have a definition of terms.

Hetty: It may be useful to make the terms hot so that upon 'mouse-over' a definition would appear.

Tom: This brings us to how we will actually survey the stakeholders. My thoughts are to post the survey online, which I can do on a private site (I would only have this survey and relevant support documentation on this site (no advertising, family photos, etc.) or place it on a CDC site. This is a minor job. The big job will be making the stakeholders aware of the survey and motivating them to participate.

Marjorie: Are you thinking of doing this on one site or having members of the steering committee help us to collect the information.

Tom: My idea is to have a single survey site that multiple sites can link to. We need the marketing power of several Consortium members' sites. A short description with a simple link or button strategically placed will be helpful in bringing the right

people to the survey. I can develop something that can be easily copied and linked to the survey site by webmasters that serve member organizations.

PHF has given me the green light to post a link from our site and to utilize our database of data professionals to e-mail information on the survey (with a hyperlink to it).

Marjorie: Since it would be time consuming and complicated to get clearance for a survey through OMB, a private site is probably the best idea. The government should not sponsor the survey.

Tom: In essence this is a Consortium survey using a site that a member volunteered for that purpose. Is this acceptable?

Marjorie: Yes, I think so.

Tom: I will plan it in this manner until I hear different. Meanwhile I would appreciate assistance in determining if there are any fatal flaws in taking this approach.

To further explain the online survey format, a template would be placed on a web page and visitors could enter their responses directly into the blank windows/spaces or click on check boxes or radio buttons to provide a standardized answer. I would, on a regular basis, download the data from the site, directly into a database table.

Michelle: Marjorie, can we place a link to the survey from the Consortium Web site that includes purpose and description?

Marjorie: I think so.

Michelle: We can send details to the Steering Committee, direct the links first to the Consortium site/WRC pages and provide the opportunity to see who is participating and what has been done to-date with the Resource Center. From here we can link to the survey.

Tom: It sounds like a great way to introduce people to the Consortium and to the Web-based Resource Center Work Group's activities.

For the survey, please consider questions that allow for short standardized answers (yes/no; A, B, C; etc. responses) to allow for easy analysis and also include some (but less) open ended questions, that are harder to analyze, yet help us expand our understanding of the needs. Please feel free to provide any constructive criticism of the draft questions.

Michelle: Are there any further modifications to the charter or minutes of the first conference call?

Note: No modifications. They will be posted to the WRC section of the Consortium Web site.

### **Action Items**

1. Provide descriptions for each of the categories.

Responsible party -Tom, other members who will e-mail ideas to him

2. Fine-tune the survey. Post the survey at private site.

Responsible party - All Work Group members are asked to e-mail critiques and new question ideas to the WRC Work Group listserve.

3. Develop a list of e-mail recipients to send our survey marketing message to.

Responsible party - All Work Group members are asked to develop a separate list that they could send the message to directly. There will likely be some duplication, but we could note this potential in our message. The duplication may provide evidence to the recipients of the importance of the survey. Please provide other Work Group members (via the listserve) with a general idea of who is on your mailing list and the total addresses.

4. Develop the orientation information at the Consortium site to introduce the WRC WG activities and the survey. Prepare the Charter and first call minutes for posting.

Responsible Party - Michelle

5. Develop and send a survey marketing message for the 'general Consortium listserve' that directs them to the orientation piece listed in action item 4.

Responsible Party - NCHS team

Note: Action item 2 should be completed prior to completion of 4 and 5. Tom will e-mail the direct link to the draft on-line survey, to all WRC Work Group members, immediately upon completion. Final comments can be sent to him at that time. When last changes are made, he will advise all members so that marketing messages can be e-mailed and the orientation/links can be posted.

Next Call Date: November 27, 2001, 11:00 am – 1:00 pm Eastern Time.

### **Adjourn**